

The Gift of Peace

Hospice care benefits the patient as well as the family

By Margit B. Weisgal, Contributing Writer

You matter because you are you, and you matter to the end of your life. We will do all we can, not only to help you die peacefully, but also to live until you die.

—Dame Cicely Saunders Founder of the Hospice Movement

rendan Connolly's mother was a vibrant, alive, active woman until the last year of her life when she was stricken with Parkinson's disease and her body started to shut down. The family chose in-home hospice care to help manage her pain and symptoms and to make her as comfortable as possible. In addition to the hospice team, she was ministered to at home by caregivers the family smilingly referred to as the "Irish Mafia," women who saw to her needs around the clock until she passed.

A hospice was originally a place for travelers to rest. The same meaning is inherent in our modern definition of hospice, a place for our life journey to end peacefully and with dignity. And it's so much more. In 1967, when Dame Cicely Saunders opened the first purpose-built

hospice, she changed the way people approach dying and death.

Although the word hospice has entered our language, many people don't understand what it is or what is involved. According to the website, aplaceformom. com, "Hospice is a special concept of care designed to provide comfort and support to patients and their families when a lifelimiting illness no longer responds to cure-oriented treatments. The focus of hospice is on enhancing the patient's quality of life, preserving the patient's dignity and dealing with the patient's end of life issues while providing emotional support for the patient's caregiver and family."

It's often confused with palliative care because the two are closely related. "Hospice care is always palliative, but palliative care is not always hospice. With hospice, the patient has received a prognosis of a life-limiting illness of six months or less so the goal is to preserve the quality of life in the time remaining and manage pain. Palliative care is introduced earlier when a diagnosis is made of a chronic disease or illness with continued therapies to prolong life," explains Dean Forman, executive director and vice president for Seasons Hospice & Palliative Care.

Both hospice and palliative care involve the patient, the family and the caregivers. What really separates them is setting priorities. Treatments can often mean a difficult and possibly prolonged period, such as recovering from surgeries or chemotherapy, sacrificing quality of life in order to extend it. The sooner palliative care is introduced, the better the results. Fewer than 10 percent know that hospice provides pain relief for the terminally ill.

"Any and all patients who are terminally ill are eligible for hospice care. It's not just for individuals who have only days or hours to live; rather, hospice is a valuable service that can offer patients physical, emotional and spiritual comfort and support for months. With their pain and symptoms under control, patients are able to focus on what is most important to them, whether it's time with family or achieving a last life's goal," explains Lori D. Mulligan, senior director of development, marketing & community services at Gilchrist Hospice Care.

Hospice is inclusive of everything you need for your loved one with almost all costs covered by Medicare so there's no burden on the family. "Mom was just going downhill and it was sad to watch the slow deterioration – little incremental changes that seemed to be happening daily. We – the whole family – needed help with managing this last stage of her life. So we contacted Gilchrist for in-home hospice care," says Melissa Wideman.

After the assessment and a consultation with her primary care doctor, a nurse visited Wideman's mother. Now, she comes by weekly to make sure her mom is comfortable. The nurse is also available to visit when her mother just doesn't feel well. A social worker visits every couple weeks; her main purpose is to support and counsel family members, to make referrals to other agencies if needed and to oversee practical concerns. Additional members of the hospice team include certified hospice aides, chaplains, volunteers, bereavement counselors and others as needed.

Although studies show that patients with life limiting illnesses who enroll in hospice care live an average of 29 days longer than those who don't, most people – around 80 percent of us – don't even think of it as an option for end-of-life

care. And, sadly, 90 percent don't know Medicare covers the costs. A majority of hospice care takes place at home, as with Connolly's mother – or wherever the patient calls home. That includes nursing and group homes, assisted living facilities and retirement communities. Fewer than 25 percent of hospice patients enter an inpatient care facility. Inpatient hospice care is most often used for short-term care to get patients' pain and other symptoms under control.

Both Seasons and Gilchrist now have care for Jewish patients that fulfill religious observance requirements, something that has not been available until recently. Seasons works with a variety of funeral homes and Chevra Kadisha when requested. Three rooms are customized at the Seasons Hospice Inpatient Center at Sinai Hospital to care for their Jewish patients, and they honor the cultural values of their patients and family members. Kosher food is provided when requested. Gilchrist offers specialized care for Jewish patients in their homes and is creating new inpatient space at Gilchrist Center Towson that is designed to enhance the experience of Jewish patients.

Gilchrist also has the largest pediatric hospice program in Maryland. "The Gilchrist Kids program was created in July 2010 at a time when there were no active pediatric hospice providers in Central Maryland. In the years since, Gilchrist Kids has become an expert voice in the provision of pediatric palliative care. Its goal is to help children with life limiting illnesses or conditions "live well" during their last months, weeks and days and to provide their loved ones with the support they need during their most difficult time. By providing relief from physical, emotional, social and spiritual suffering, we enhance the quality of life for seriously ill children and their families," according to its website, gilchristservices.org/kids.

Conversations about the end of life are difficult. Discussing hospice as an option is worth including when you make your plans on what you want and how you want to be cared for. Your wishes should be in writing to avoid any misunderstanding. When someone dies, we often say, "Rest in peace." Hospice helps make that so. •